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ABSTRACT

Many efforts in providing training programs for parents of handicapped children have not provided for adequate parental input. Implications of reviewing previous efforts in advocacy programs indicate a need to develop a more systematic approach in both obtaining information on parental involvement as child advocates and in developing training programs that meet their perceived needs. Implications for future special education in the area of training parents as effective advocates include such efforts as recognizing and providing for parental input and evaluating the effects of advocacy training for the parent and the exceptional child. (Author/SBH)

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A Data Based Approach to Training Parents of Handicapped Children As Effective Advocates

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A Data Based Approach to Training Parents of Handicapped Children As Effective Advocates

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Running head: Training Parents as Advocates

Abstract

In reviewing previous parent advocacy training activities, there has been a noticeable lack of systematic data about how advocacy is accomplished and the type of results achieved. Perhaps of equal importance is the lack of mandates for future advocacy activities. Many efforts in providing advocacy training programs for parents of handicapped children have not provided for adequate parental input. Training needs are specific to various locales. However, designing a model based on perceived needs of parents can be adapted for use beyond a specific geographical area. The authors discuss a suggested model for training parents based on perceived needs and implications for future advocacy training.

A Data-Based Approach to Training Parents of Handicapped Children as Effective Advocates

Every professional having contact with an exceptional child has the responsibility of assisting the parent to be an effective agent in obtaining necessary support and services for both parent and child. This basic attitude of training parents in relating effectively to and receiving services from child serving agencies, institutions and other similar systems can be defined as advocacy. The term "advocacy" has often generated confusion, inconsistency, setbacks, and uncertainty (Biklen, 1976). Part of this confusion has been caused by a lack of systematic data about how advocacy is accomplished and type of positive results achieved (Kahn, Kamerman, & McGowan, 1972). In the Report of a National Baseline Study of 102 child advocacy programs in the United States, including those with federal level funding, not only was there a lack of systematic data but also a lack of mandates for future advocacy activities. (Biklen, 1973; Kahn, et. al., 1972).

Without mandates for future directions of advocacy activities, professionals and consumer groups must survey the problem or need unique to local service areas and develop parent education programs based on this informed study. In this sense, advocacy is not a transportable commodity. While we can learn some general techniques and skills from each other in developing training and education programs for parents of exceptional children, needs assessments and activities to strengthen advocacy roles are unique to each country and perhaps, unique to local geographic areas within the same country.

Parent training programs are not new or unique. However, they have

often been designed according to needs as perceived by the professional rather than the parent. Many of the efforts in providing advocacy programs, with the exception of a few national, parent-directed advocacy groups, have not provided for adequate parental input. As a result, there is little information concerning the present advocacy activities engaged in by parents; likewise, there is little information concerning their prospective future activities.

While parent training activities are not new or unique, certain events have occurred in the United States of America (USA), to ensure a commitment by professionals to seek more effective ways of strengthening the relationship and interactions with parents on behalf of exceptional children. First, there has been a renewed commitment on the part of educators to plan and work with the "whole child" and the many factors in the environment that interface with the life of the exceptional child; second, parents are seeking skills and support from professionals and other parents to deal more effectively with their children at home and with support service agencies; and third, federal and state laws have mandated parental involvement in the educational decision making process.

In preparing to meet future training needs of parents in the state of Arizona, USA, a survey was conducted with parents of severely handicapped children. Two hundred eighty three parents completed the survey. The parents were first asked to indicate the types of services, information, and/or support they have sought regarding their handicapped child. The general headings included educational areas, medical areas, community and government agencies. They then rated the quality of the service or information received and evaluated their own effectiveness in obtaining or using the needed service.

In the area of education, over 70% of the parents had contact with special education teachers, educational specialists such as speech therapists and educational administrators. Only half of the parents had contact with the regular classroom teacher or psychologist. Of those parents having contact in the educational field, over 80% rated the quality of the service or information received from special education and educational specialists as positive. They also rated their own effectiveness as positive in both cases. The quality of service or information from educational administrators, psychologists and regular classroom teachers was rated as positive by approximately 55% of the parents having contact. Less than 40% of the parents had contact with agencies, community services, or individuals, such as counselors or social workers. Of those contacting legislators only 28% rated the quality as positive, and only 26% rated their own effectiveness as positive. Parents also felt they were not effective in securing services/information from religious organizations, state personnel, general/medical practitioners, or community services including local organizations such as Boy Scouts and recreational programs.

Between 60% and 70% of the parents sought information/support from friends, family, parent groups, and individual parents of handicapped children. Of these categories, contact with individual parents and parent groups was rated highest in terms of quality; contact with the family was rated lowest.

In analyzing the responses of parents according to groups, the following trends were noted. In terms of seeking affiliation with other parents of handicapped children, parents of the retarded, learning disabled, and autistic sought out parent groups and individual parents, whereas the

majority of the parents of the blind or physically handicapped children did not have this contact. The majority of the contacts with State Personnel were made by parents of the mentally retarded and parents of the autistic. The learning disabled group, however, was the most active in contacting legislators (approximately 60%). Only 8% of the parents of the blind and physically handicapped had any contact with legislators.

The second half of the survey was directly concerned with advocacy activities. Douglas Biklen, in his book, Let Our Children Go: An Organizing Manual for Advocates and Parents, discusses twelve advocacy activities that can be effective in securing needed services or rights for children. Parent responses to the second half of the survey are shown in Tables 1 and 2.

In Table 1 the percentage of parents participating in these advocacy activities is listed. As indicated, over half of the parents had written letters of complaint or support concerning delivery of services on behalf of their children. Other areas of active parent participation included development of community education programs, communication materials, and negotiations with service delivery systems for policy changes or initiation of new services. Again, the most active groups were parents of learning disabled and autistic children. These findings are in concordance with the more active involvement of parents of learning disabled and autistic children previously noted with regard to parent group affiliation, state personnel and legislator contacts.

INSERT TABLE 1 ABOUT HERE

The parents were then asked to indicate which skills or services, from a listing of 25, they felt they needed in order to be more effective

advocates for their children. The skill areas in Table 2 are ranked according to need as perceived by the parents participating in the survey. Of the activities listed, 64% of the parents indicated that having more information regarding services available for their children would be their first priority in attending meetings, workshops, or other training activities. More than half of the parents indicated they would seek activities that would (1) provide more information regarding support services for themselves as parents as well as support services for their children, (2) provide information on how they could effectively communicate with service delivery systems prior to making contact, and (3) train them in developing skills in order to be effective advocates for their children.

INSERT TABLE II ABOUT HERE

Implications of reviewing previous efforts in advocacy programs indicates a need to develop a more systematic approach in both obtaining information on parental involvement as child advocates, and in developing training programs that meet their perceived needs. Based on this information, a model for training parents in developing skills to be effective advocates on behalf of their children can be formulated. Such a model should address not only advocacy skill training for parents, but for those involved in service delivery systems who also advocate for the welfare of handicapped children.

Rutherford, in a paper presented to the American Association for the Education of the Severely and Profoundly Handicapped, discussed a model of training and information which has implications for future planning in advocacy efforts (Myers, Haynes, and Rutherford, 1977). The model

identifies two recipients of training and information: parents and service delivery systems. The areas of training include early identification, educational decision making and community activities. The types of training and information under these three areas include values clarification, assertion training, communication skills, applied behavioral analysis, and behavioral objectives.

Parents and service delivery systems would determine the depth of training needed in these areas. By providing parallel training to both parents and service delivery systems, advocacy efforts would be combined and strengthened.

Implications for future special education in the area of training parents as effective advocates include:

(a) recognizing and providing for parental input in advocacy training programs conducted by professionals;

(b) developing assessment instruments that will provide information as to perceived needs and skill levels of participants in advocacy training efforts;

(c) designing advocacy training models based on systematic collection of data;

(d) providing parallel training for parents and service delivery systems;

(e) evaluating, in a systematic fashion, the effects of advocacy training of procurement of services and information for the parent and the exceptional child;

(f) reevaluating traditional concepts of parent training;

(g) developing parent education and training activities on three levels--awareness, information, and skill development;

(h) disseminating information on needs assessments, informal surveys, and results of training, and training models on a national as well as a worldwide basis.

These implications for future involvement in training parents as effective child advocates can be generalized to any location. The efforts to put viable programs into effect are unique to specific locales. The results of each local effort, how the training was designed and implemented, have significance for all professionals committed to working with exceptional children and their parents. Activities such as we are participating in today will assist in strengthening these efforts. We seek to improve each other's skills in ways that are transportable from one country to another, let us hope that this effort will continue.

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TABLE I

Biklen's Advocacy Related Activities

and Percent of Parent Responses

Participation of Parents	% of Parent Participation
Wrote letters of complaint or support to administrators, legislators, or others concerned with delivery of services.	52%
Developed or helped develop community education programs regarding such things as education of the handicapped and legal rights.	33%
Developed or helped to develop communication materials or networks to inform the public of the needs of handicapped children.	26%
Negotiated with a service delivery system to have them change policies or provide new services.	26%
Issued or helped develop a list of demands as a position statement.	25%
Testified or helped prepare testimony for a public hearing concerning services for handicapped.	24%
Lobbied for legislative change or administrative policy change.	23%
Led or participated in a demonstration.	19%
Developed or helped develop a model program as an alternative to current system.	16%
Took legal action in relation to a child's rights to service.	6%
Initiated or participated in a boycott of a service delivery system.	3%
Participated in a symbolic act to call attention to a policy or practice or need that deserves exposure.	2%

N - 283

TABLE II

Skill Training Needed for Effective Advocacy as Perceived by Parents of Handicapped Students Surveyed N = 283

Skill Areas	Rank	%
Have more information regarding services for my child	1	64
Have more information regarding supportive resources available	2	59
Have more information prior to seeking services, etc.	3	54
Have special training	4	50
Be more aggressive	5	44
Have fewer conflicting responsibilities	6	44
Have more information regarding my child's handicap	7	43
Have more time with professionsals	8	43
Attend more workshops	9	43
Be more assertive	10	42
Have the skills to ask appropriate questions	11	40
Meet with other parents with similar interests	12	38
Have easier access to professionals	13	36
Talk with persons having similar problems	14	30
Understand the information received	15	26
Have more support from my spouse	16	25
Have counseling opportunities	17	25
Organize other parents with similar interests	18	24
Have more time for advocacy activities	19	24
Have respite care	20	20
Be less passive	21	17
Have immediate crises support	22	17
Be more passive	23	7
Be less aggressive	24	4
Be less assertive	25	2